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ABSTRACT

Two brief fact sheets for families of children with disabilities provide basic information on: (1) assistive technology within the family setting, and (2) the concept of parent management of a technology team. The first fact sheet briefly defines assistive technology and discusses technology for physically and mentally challenged individuals, differences between high and low technology aids, examples of assistive technology aids, and identification of assistive technology needs. The second fact sheet offers a rationale for families playing a key role on the technology team, outlines the role of parents as team managers, and gives suggestions for selecting team members. Five suggested resources and publications conclude the second fact sheet. (DB)

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What Is Assistive Technology and What Can It Do for Me or My Family?

[and]

Creating a Family-Driven Technology Team

Key Notes

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TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)

What is assistive technology and what can it do for me or my family?

A New Age....

This is the age of new technological advances. As new inventions and discoveries which were out of reach for most persons only a decade ago have become commonplace, we have seen the benefit in our daily lives. When we were children, we saw large expensive computers calculate numbers. Now we simply press a few buttons on our inexpensive home calculator and our answer quickly and accurately comes up. We have found that the exception a few years ago is now the rule. Technology in our lives has become commonplace. An example is the invention of "velcro" for the space program. Daily, velcro fastens and keeps things in place for us.

Technology assists many of us in our daily lives. The term "assistive technology" comes from the meaning of the word "assistive." The dictionary defines "assistive" as "giving help or aiding". For abled-bodied people, the world is full of assistive devices that make life easier and more productive. Calculators help figure our grocery bills. We use our TV's remote controls to change channels while we sit on our sofas; and we use microwave ovens to cook our meals faster. Just as these and other modern "machines" help able-bodied people do things more quickly or more easily, they are used by people who have disabilities.

Technology for physically andmentally challenged individuals:

Technology has become essential to persons challenged by severe mental and/or physical disabilities. The world need not be a frustrating place for them. Personal and environmental limitations that created barriers and limited opportunities for these individuals to interact with nondisabled family members and friends, can now be overcome through the same simple technology that people without disabilities use. (Assistive) Technology has increased access to new experiences, new activities, and new environments, bridging the gap imposed by a physical or mental disability. (Breaking Barriers, J. Levin, L. Scherfenberg, 1986)

High Tech or Low Tech

Many professionals have concentrated on more complicated technology--sometimes called "high tech," for "high technology." This includes computers, as well as augmentative communication devices, which speak for people who cannot be understood well by others. However, this type of equipment can be expensive and most people need training to use it.

Assistive technology also includes more simple equipment--sometimes called "low tech," or "low technology." These things make life easier, but are less expensive and require little or no training. A door lever makes it easier for a child in a wheelchair to open a door; elastic shoe laces help the child with poor motor skills put on his shoes; and a plate switch allows the child with mental disabilities to play with battery-powered toys by hitting the switch with his/her hand.

High tech or low tech, assistive technology opens up new opportunities for individuals

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with disabilities to participate with family, friends, and peers in home, school, work, and community settings.

Assistive technology includes aids that:

- make things easier to turn on (for example, adaptive switches or large knobs)
- hold things steady or in place (for example, velcro or clamps)
- help a person get dressed, eat, or bathe (for example, bath chairs or built-up spoons)
- help a person learn (for example, tape recorders, computers, or "Talking Books")
- help a person play games or relax (for example, electronic card shufflers, page turners, or large dice)
- help a person get around more easily or quickly (for example, wheelchairs or walkers)
- help a person talk with other people (for example, electronic communication devices)
- help a person see or hear better (for example, magnifiers or hearing aids)
- help people control things at home or work (for example, remotes to turn on lights and talking computers)

Assistive technology is frequently overlooked because families do not realize all the implications for daily use. Simply taking an inventory of a child's daily activities may reveal activities or tasks in which an assistive device could be used:

- **frustration with communication**... can be helped with a device that can speak for the child so that everyone can understand
- **difficulty with bathing** ... can be helped with bath chairs, lifts, and other bathing aids
- **feeding and eating**...can be helped can be adaptive devices like built of spoons
- **helping make leisure and play activities independent**...can be aidedwith adapted toys and modified sport equipment

These and other examples may lead one to examine the child's home and school environment with assistive devices in mind. If the child has a need, there is probably an assistive device available which could help.

Finally....

What is assistive technology? It comes in many colors, shapes, and sizes. It may cost a little, it may cost quite a bit. It may require continual training or no training at all.

The assistive technology needed for one family may be different from the technology needed by their neighbor or friend. But for most of us, technology will be a "fact of life" to help us as well as the child with disabilities.

KEY NOTES are created by THE ACCESS GROUP to provide information about assistive technology to the families of Vietnam veterans who have children with disabilities. THE ACCESS GROUP is jointly funded by the Agent Orange Class Assistance Program and United Cerebral Palsy Associations, Inc. If you are a family member or a professional working with families of Vietnam veterans, THE ACCESS GROUP can serve as a resource to you in your efforts to obtain assistive technology. This publication is also available on audiotape. For more information call: 1-800-821-8580, 1-404-888-9098 (TT).

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Creating a Family-Driven Technology Team

Today, for a child with disabilities, technology plays a growing role at school, at home, and in the community. To help make technology work well, working hand-in-hand with professionals as a team is a MUST.

Families are members of a variety of teams which can support their child. These teams include:

- medical teams - for resolving medical issues.
- educational teams - for meeting the child's learning needs
- rehabilitation teams - private/public programs supporting the child's developmental needs outside the educational program
- homecare teams - for helping with babysitting, play groups, etc.

WHY FAMILIES?

Why should families play a key role in making plans about technology, in using technology with their children, and in keeping track of what is done by others?

First, parents are both willing to and capable of being partners in planning for their child's technology needs. They know what their child has difficulty doing and that using a device often makes the task easier.

Second, parents are the life-long "cheerleaders," managers, and moment-to-moment participants in their children's lives. They are there when professionals aren't, and they are there for the long haul.

Third, they are in the best position to make decisions about how well equipment works or doesn't work for their child outside of school, clinics, and technology centers.

Fourth, both the law and standards of "best practice" are on the side of parent directed involvement in their children's lives. For example, parents must be included as team members when IFSP's (Individualized Family Support Plans) and IEP's (Individualized Education Plans) are developed and used.

Bruce Lindemann (1991), a parent of a child with a disability, captured the feelings of families everywhere with this statement:

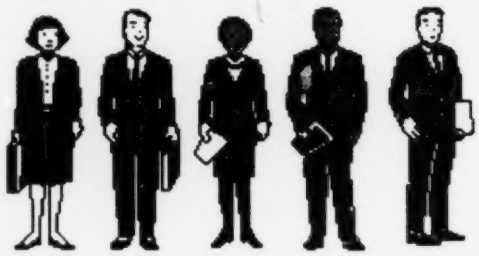
"It is the family who is the one constant, motivating force behind the development of the child with special needs. It is the family who becomes the self-made advocate of the medical and therapeutic services, education and recreational programs for its child with special needs. It is the family who implements the medical, therapeutic and educational programs after the child leaves the hospital, clinic, or classroom."

Fifth, parents (with their long-term experience regarding their child's disability, needs and use of devices) have often researched technology supports and are in a position to offer information, training, and support to the rest of the team.

Clearly, family members can and should be the managers or leaders of teams that make

decisions about technology for children. Such teams may naturally form during the evaluation/ equipment identification process; during periods of IEP development and review, and as transition planning is written for the older child. However, technology teams can be established independent of educational settings as part of outside private therapies, during the process of buying a computer for the home, and in support of parent training needs.

Family-driven technology teams may be composed of teachers, therapists, vendors, social workers, consultants, or interested individuals. The family may have more than one technology team and these teams may be on-going or short-lived. The primary team leader though, remains the parents who can provide the continuity between team members. Since ongoing management of children's long-term technology use should and actually does rest with families, parents should learn the secrets and techniques for being effective managers, just like managers in business.



WHY TEAMS?

(Many of the following points were taken from Managing Relationships At Work, The Atlanta Consulting Group, Inc. 1984. Their materials have been adapted to apply to the family member as manager of his/her child's technology team.)

With the development of communication and learning technology tools, families now need a technology team that can offer the planning assistance needed to incorporate technology into other aspects of the child and family's daily living.

On a technology team, family members work with others, usually professionals, to reach the technology goals they have set for their children. Traditionally, a professional takes on the role as manager of the technology team, with the parent playing a smaller role. In too many cases, parents are asked only to supply information about what their child can and can't do. Since many parents have had little chance to learn about new technology, their role in decisions about technology is usually even less than in typical educational planning.

Too often, the information that families have is not heard or is discounted as being "out of sync" with the views of professionals. Further, families are left out of the information loop about technology, how it works, what it can do, and how best to use it in real life. Traditional views about who should be in charge, combined with a lack of comfort with new, often complex information about the whole new field of technology, puts many families in the position of being a "second-class citizen." Despite the move by forward-thinking schools and programs to be family-centered and even family-directed, there are few opportunities for parents to be a meaningful part of the child's program planning team. Therefore, the family's ideas about what is important for their child are too often ignored.

Parents as managers need to:

- ☑ ***Coordinate the gathering of information***
- ☑ ***Work with all key players*** (family and professionals) to identify resources for the child
- ☑ ***Keep track of what is happening***
- ☑ ***Deal with problems as they arise***

However, the most important role of the manager is to ensure that people who have the skills and resources are working as a coordinated team to meet the agreed-upon goals for the child.

WHY MANAGERS?

Overall management and coordination of people and services is often the most difficult task for anyone, whether it is in the area of technology, planning a block party, or getting ready for a family vacation. The following strategies are recommended for the family technology team manager:

1. Plan:

- *set goals*
- *develop an action plan for reaching these goals*
- *continually evaluate progress toward goals*
- *make adjustments based on evaluation*
- *set new goals based on accomplishments.*

2. Implement:

To make it possible for plans to be accomplished, good managers must view all the team members (professionals and family members) working with them, as fully capable of doing their best.

- *understand what needs to be done*
- *look at team members abilities and potential*
- *assign tasks to the right people*
- *be sure each person gets the right training and support they need to get the job done. (ie. teachers get training on the equipment that the child uses as part of their educational program)*

3. Motivate:

To motivate, the family manager must:

- *observe (how things are going)*
- *listen (to the team members)*
- *get feedback (either written or by telephone, know the needs and desires of the person doing the task)*
- *confront (set deadlines, ask questions, know what the task will require or demand of the people who are responsible for accomplishing that task)*
- *negotiate (make adjustments while constantly striving to achieve the established goals)*
- *sell (if you believe - convince others)*

4. Visualize:

Have a mental picture of what you want your child to become (VISION). Set your goals according to this vision. **Vision is at the heart of effective family technology management.**

The family manager's vision makes it possible for people to see how their parts fit into the overall plan. This vision helps the team members to work as a group with similar plans and goals.

The family manager must be able to

- *put the vision into words that others can understand*
- *get the team to agree on the same vision*
- *keep everyone focused on the vision without veering off*

WHO IS ON MY TEAM?

Getting the right people who have the skills and resources to make up your technology team should not be a difficult task. Typical team members may already be on your medical team, educational team, or therapy team. However, other less obvious persons should be considered.

Unique Team Members:

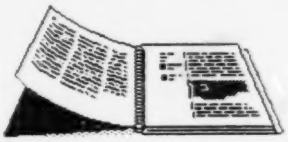
A key person should be someone with some technical background..... who understands how computers or other electronic systems work. Many times this individual may be a friend or acquaintance. It may also be a parent of a child with a disability who is already using the equipment that your child needs. However, it is important to work with someone that understands how to use, maintain and upgrade the technology with which you are working.

Someone who sells the equipment (vendor) may need to become part of the technology team. It is important to establish a personal relationship with a vendor from whom you have or are planning to purchase equipment. Get to know their name; make sure they know your name and something about your child; help them to understand your needs for now and the future.

A technology advocate is someone that can with help you understand the law, school policy, and your child's civil rights as they pertain to technology. This type of person is relatively new in the arena of technology for individuals with disabilities. However you may find someone through such organizations such as The Alliance for Technology Access, Parent Training and Information Projects, and non-profit organizations such as United Cerebral Palsy Associations, Easter Seal Societies, and Lekotek or Compuplays.

Another parent who is working with the same issues. Frequently, parents can give emotional support and insight into the plan or path that they took to achieve technology goals for their child.

The family technology team can be an effective tool for accomplishing not only the child's technology goals but also in effecting change in the areas of social, educational, and community life. An effective family manager can create "win-win" situations that ultimately offer the child with disabilities a consistent program. Through the family-driven technology team a child's technology future is shaped to integrate him more fully into the family and community so he/she becomes a more productive human being.



Suggested Resources and Publications:

Apple Computer Resources in Special Education and Rehabilitation, Edited by Gary Moulton, 1990, DLM. One DLM Park, Allen, TX 75002

Assistive Device News, Central PA Special Education Regional Resource Center, 150 South Progress Avenue, Harrisburg, PA 17109

Exceptional Parent, 1170 Commonwealth Avenue, 3rd Floor, Kenmore Station, Boston, MA 02134

Independence Day, Designing Computer Solutions for Individuals with Disability, Peter Green, Alan Brightman, 1990, DLM, One DLM Park, Allen, TX 75002

Managing Relationships At Work, 1989, The Atlanta Consulting Group, Inc. 2028 Powers Ferry Road, Suite 190, Atlanta, GA 30339 404/952-8000

Special Magic, Mary Male, 1988, Mayfield Publishing, 1240 Villa St., Mountain View, CA 94041, 1-800-433-1279

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